Information in practice

An information system and medical record to support HIV treatment in rural Haiti

Hamish S F Fraser, Darius Jazayeri, Patrice Nevil, Yusuf Karacaoglu, Paul E Farmer, Evan Lyon, Mary Kay C Smith Fawzi, Fernet Leandre, Sharon S Choi, Joia S Mukherjee

Lack of infrastructure, including information and communication systems, is considered a barrier to successful HIV treatment programmes in resource poor areas. The authors describe how they set up a web based medical record system linking remote areas in rural Haiti and how it is used to track clinical outcomes, laboratory tests, and drug supplies and to create reports for funding agencies

Brigham and Women's Hospital, Division of Social Medicine and Healthcare Inequalities,75 Francis Street, Boston, MA, 02115, USA
Hamish S F Fraser *instructor*
Paul E Farmer *professor*
Evan Lyon *medical resident*
Joia S Mukherjee *instructor*

Partners In Health, 641 Huntington Avenue, Boston, MA, 02115, USA
Darius Jazayeri *computer scientist*

Zanmi Lasante, Cange, Haiti
Patrice Nevil *engineer*
Fernet Leandre *physician*

Program in Infectious Disease and Social Change, Harvard Medical School, 641 Huntington Avenue, Boston, MA, 02115, USA
Yusuf Karacaoglu *engineer*
Mary Kay C Smith Fawzi *instructor*
Sharon S Choi *research assistant*

Correspondence to:
H S F Fraser
Hamish_fraser@hms.harvard.edu

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HIV/AIDS has become the world's leading infectious cause of adult deaths[1] and takes its greatest toll in remote, resource poor areas. Dramatic improvements in survival have been seen with use of antiretroviral drugs in developed countries[2] and in Brazil.[3] Since 2001, substantial resources have been pledged to treat HIV infected patients in developing countries,[4] but concerns have been expressed that many such countries lack the infrastructure to support the complex treatment regimen for this chronic disease.[5 6] This article describes approaches to improving important infrastructure components for HIV treatment in very impoverished areas—clinical communications, data analysis, and drug supply management.

Background

Haiti is the poorest country in the western hemisphere and, with about 6% of adults infected with HIV, is the most severely affected by HIV/AIDS.[7] Six years ago the non-governmental organisations Partners In Health and Zanmi Lasante launched an innovative, community based HIV treatment programme in Haiti's impoverished central plateau.[8] Zanmi Lasante currently monitors more than 7000 patients with HIV, of whom more than 1300 are currently receiving highly active antiretroviral therapy (HAART). In 2002, Zanmi Lasante was awarded part of Haiti's grant from the Global Fund to Fight AIDS, Tuberculosis, and Malaria (GFATM)[4] to expand this successful programme to five more sites in the central plateau—Thomonde, Lascahobas, Boucan Carre, Belladere, and Hinche. Zanmi Lasante runs a central hospital housing the laboratory and main drug warehouse, with a second laboratory recently set up in Lascahobas and smaller pharmacies and laboratories in the other sites.

Highly active antiretroviral therapy requires daily administration of three antiretroviral drugs to maintain control of the disease and to minimise emergence of resistance.[9] Scaling up care to thousands of patients requires good information management to ensure that each patient can be identified and traced, that his or her health status is monitored effectively, that results from critical laboratory tests are monitored and communicated to doctors, and that drug supplies are always available at each site. Implementing this rapid treatment expansion in a region with few doctors and virtually no roads, electricity, or communications is a major challenge. Zanmi Lasante's initial experience, in Cange, of access to the internet via a satellite link suggested that establishing communication with the new sites was feasible with new technologies to leapfrog the lack of infrastructure and that electronic record keeping was feasible and helpful in programme and patient management (fig 1).

Information and communication

Medical information can be a critical lifesaving resource,[10] but staff in remote hospitals often have to function almost entirely on their own, without access to up to date medical information or the support of more experienced colleagues. This situation is changing with

Fig 1 Clinical staff in Belladere, rural Haiti, find their web based medical record system helpful for managing patients with AIDS

Box 1: Technical details of satellite systems

The main site (Cange) has a 256 kbs bidirectional link, using the USA Teleport Satellite signal, connected to a local area network (LAN) which provides broadband connection to the internet (256 kbs fractional-T1 line). The expansion sites have lower cost systems from Skycasters. Equipment includes a satellite dish and satellite modem that plugs into a standard PC server or a router. The asymmetric connection provides 400 kbs or better download speed but 30 kbs upload speed on the basic configuration, upgradeable to 64 kbs. The cost of basic hardware including the server PC is currently $6000 (£3260; €4695), and monthly charges range from $130 to $260 depending on bandwidth. These specifications are similar to those for "Mini VSAT" satellite networks in west Africa and South Africa.

For connecting different buildings in a site, we use a standard Ethernet LAN or wireless LAN (802.11). Wireless technology allows low cost connection by avoiding additional wiring costs, and "in line of site" connections can be made up to 12 km at low cost ($1000).

increasing access to the internet, particularly with the expanded use of email.[11] Consultation can include sending digital camera images, termed "store-and-forward" telemedicine.[12 13] Our treatment sites in Haiti, Peru, and Russia have used email extensively over the past decade for clinical communication and logistics. Our experience in the original Haitian site, Cange, indicated that the cheapest and most flexible communication strategy was to establish a small satellite connection to the internet in each of the five new sites (box 1).

Medical data management

Despite the value of email for supporting patient care, lack of structure and organisation limits its potential as the sole information management tool. Email also lacks good tools to ensure security and confidentiality of data. Creating a database of core information allows staff to track individual patients as well as to monitor the care of an entire group. For patients with HIV, this includes tracking critical laboratory results such as CD4 counts.

The traditional approach to electronic data management in a remote location is to place servers in the clinic sites,[14] and in some systems data are periodically transmitted to a central server.[15] In rural Haiti this is problematic because of unstable electrical power, humidity, dust, security concerns, and difficulty in providing technical support. Implementing a secure, web based electronic medical record allows data collection and review to occur from many remote sites. Using a shared server in a secure environment with stable power and good data backup (including a duplicate machine off site) has the additional advantage that the most recent data are available to all users. Scaling up treatment also calls for training new health workers; using decision support tools may assist them to become familiar with the management of HIV.

The HIV electronic medical record

The HIV electronic medical record (HIV-EMR) is based on the technology we developed for a web based tuberculosis electronic medical record in Peru[16] (box 2) and is hosted on a server in Boston, USA. Clinical data forms include demographic data, clinical assessment, laboratory investigations, and social circumstances (box 3) and are based on the paper forms that Zanmi Lasante has used for several years. The electronic medical record was developed in French and English, with close consultation with local Haitian users to ensure it supported their needs. The system includes a library of web page analyses, developed for a related project,[16] that simplify searches for patient groups based on characteristics such as age, drug regimen, and laboratory results. Other pages generate graphs and tables and allow data to be downloaded to statistical analysis packages.

Box 2: Technical details of the HIV-EMR

The HIV-EMR is based on the web based electronic medical record we developed to support a treatment programme for drug resistant tuberculosis in Peru.[16] It is built with standard, open source software—Linux operating system, Apache web server, the Tomcat Java Servlet engine. We are using an Oracle database, but an open source database is being considered to allow free distribution of the whole system.

Drug supplies and use

A crucial part of treating HIV infection or other complex chronic diseases in developing countries is ensuring an uninterrupted supply of drugs. This includes procurement, shipping, storage, and issuing to patients. Accurate information on current stocks and estimates of future requirements are crucial to ensure optimum prices and avoid stocks running out or passing their expiry date. In the HIV-EMR drug regimens are recorded for all patients receiving treatment. We can calculate the total requirements for a patient group for a specified period based on their prescribed regimens.[16 17] This is useful when treating a large cohort with one disease type, especially when the number of treated patients is expanding rapidly. An alternative approach is to calculate the amount of drugs that enter and leave the warehouse each month, typically with WHO stock cards, to assess use. Several database systems have been developed to automate this process, but they generally need servers at each site.[17 18]

The HIV-EMR supports both of these methods. Web pages representing stock cards provide a familiar interface for staff to keep track of drugs in the warehouse. Recording drug regimens and use in one networked system allows automatic cross checks of

Box 3: Categories of data collected in HIV-EMR

- Patient demographics
- History of presenting complaint
- Previous treatment and any adverse events
- Symptoms
- Physical examination
- Laboratory investigations
- Social circumstances, housing, occupation
- Drugs
- Narrative text is also allowed in some categories such as clinical history and assessment

estimates from both methods, and enables the geographically dispersed drug procurement team to share the same data and analyses.

Data security and confidentiality

To develop a web based electronic medical record for this project, we built on extensive previous work on encryption and web security for financial transactions and medical records.[19 20]

- Users are required to have complex passwords and can access only the parts of the site they need
- All logins and viewed pages are recorded and reviewed to ensure that no unauthorised access occurs
- A centralised database allows the computer and data to be physically secure and backed up regularly
- The capability to view patient details securely in the electronic medical record removes the need to send patient information by non-secure email
- Encryption of data transfers is done with the Secure Sockets Layer (SSL) protocol.

Current experience with the HIV-EMR in Haiti

Communications

Zanmi Lasante staff have fully adopted email to coordinate care between sites. This includes scheduling and obtaining the results of specialist investigations in the capital, Port au Prince, or the United States, organising patient transfers for surgery, and ensuring staff are ready for emergencies. Email consultation with doctors is done daily, especially by junior staff in remote clinics, who often require advice on treatment options. Patient names and addresses are excluded from non-secure email. Email also assists in ordering and monitoring shipments of drugs and equipment. Medical information websites are also used extensively.

Use of the HIV-EMR

The HIV-EMR has been operational for over nine months and is accessible at the six sites in the central plateau. Doctors and nurses enter all clinical and drug data using a standard patient registration form. To speed data entry, the form has a checklist to order patient management items, including investigations and standard sets of drugs (fig 2). Once this form has been submitted, the subsequent page displays any drugs that were selected. Doctors can check the drugs, their doses, and the times of day to be administered. Finally, when submitting this form, the user can print out an order for the pharmacy. As drugs are entered, they are cross checked for allergies, inappropriate doses, and incompatible drug combinations. The system displays warnings about any problems detected, such as prescribing zidovudine and stavudine together.

Decision support is also used for laboratory results. Technicians in two clinical sites, Cange and Lascahobas, enter CD4 cell counts. Each night, a program checks for patients with low CD4 counts who are not receiving the appropriate drug regimen. A warning email is sent to all 20 Zanmi Lasante clinicians and contains a link to the electronic medical records of patients who require additional treatment. Reminders can also be generated for patients who require extra drugs or investigations.

Currently more than 150 new cases are entered each month, mostly via the "Offline EMR" (see below).

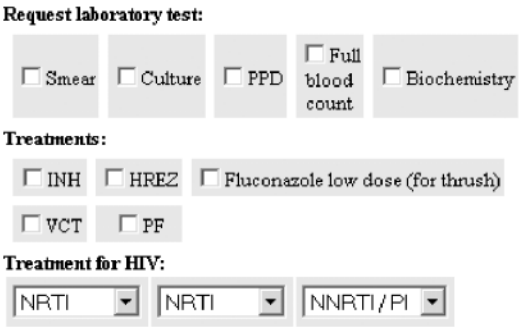

Fig 2 Part of the checklist of items in the patient registration form of the HIV-EMR electronic medical record (PPD=tuberculosis skin test, INH=isoniazid, HREZ=four standard antituberculous drugs, VCF=voluntary counselling and testing, PF=family planning, NRTI and NNRTI/PI=antiretroviral drug lists)

Of the 2500 cases that have been entered, more than 1300 have full registration data and vital signs, and 800 have full antiretroviral drug regimens recorded. Drug stocks in the warehouse are recorded regularly by the pharmacists using web based stock cards. Regular analyses monitor the expected drug use from the drug regimens entered.

Problems and challenges

Offline data entry

Loss of network connection regularly interrupts the use of our web based system, especially in the rainy season. We therefore developed the "Offline EMR" for offline data entry. This includes the core functions of the web based system but stores data on the local computer. When the network becomes available again, it transmits data to the server using a secure web connection.[20] Entered cases can be stored for an unlimited time, but delays in uploading the data increase the risk of their loss because of computer problems. Case summaries are stored in password protected, secure form in the application and are updated when an internet connection is available, allowing updates and changes to be made to existing cases. Periodically, the application needs to be updated or fixed: to reduce the need for IT staff to visit remote sites, the application can be tested and upgraded over the internet.

Patient identification

Low literacy in Haiti contributes to inconsistent spelling of patients' names and addresses. We have developed search tools to match duplicate records based on name, address, age, and sex, and then either merge the two records or email the details to the users for advice. Use of patient identity cards may be helpful once the system is not limited to HIV patients.[21]

Data quality

Initial training sessions are held on site with clinicians by IT staff, and follow up visits are made regularly. Data forms contain checks for out of range values. Data checking and cleaning are done by means of web based forms as well as email support for clinicians.

Usability

Training and time requirements to keep the data in the electronic medical record up to date are vital for sustaining the system. Although our doctors have been able to

complete the patient intake forms effectively, we recognise the need to provide more support for follow up data and data quality checking as the electronic medical record system expands to thousands of patients.

Discussion

Global experience in treating HIV in resource poor areas, including information management, is limited. Electronic medical record systems to support HIV treatment date back 10 years to Safran et al, who developed an ambulatory medical record component of the information system at Beth Israel hospital in Boston.[22] Their system included email alerts for doctors about patients with low CD4 counts, and they showed it improved quality of care.[22] Our HIV-EMR system shows that effective information management is also possible in a poor community with no modern infrastructure. The electronic medical record and communications systems continued to function even during the armed uprising in Haiti this year.

Box 4 describes existing systems for HIV information management in developing countries. The strategies for information management vary depending on the nature of a particular treatment programme, the number of sites where patients are treated, and the available infrastructure and human resources. Stand alone databases have the advantage of being easier to develop and maintain, but they typically lack valuable tools to coordinate data between sites. The use of guidelines and alerts to guide prescribing has been shown to improve the quality of treatment and reduce medical errors in developed countries.[23] Given the limited experience in treating HIV in developing countries, decision support may have an important role, but this requires further evaluation.

Cost is a major concern with any technology intended to be used in very poor areas. Can the expenditure be justified with so many other pressing needs? The annual cost of internet access per site in Haiti is $1600, equivalent to about two years' highly active antiretroviral therapy and clinical care for one patient. Capital costs of $6000, along with staff training and assistance with data entry, increase the overall expense. This must be balanced against potential benefits including support for clinical care and research; our drug costs alone are currently more than $500 000 a year and rising. Strict reporting requirements by funders such as the Global Fund provide further incentives for effective monitoring.

Conclusions

HIV-EMR has proved itself in some of the most challenging field conditions in the world, similar to those found in much of sub-Saharan Africa. Future work will focus on refining the system and developing a core data set and functions to support other HIV treatment projects, including incorporation of data representation and exchange standards such as Health Level Seven document architecture.[28] Common standards for creating computerised guidelines are also important to allow sharing of knowledge between projects and information systems.[29]

Sharing of ideas, models, and software (such as the Offline EMR) between projects is essential if we are to

Box 4: Examples of information systems to support HIV treatment in developing countries

Stand alone databases

- The Brazilian public health system currently delivers antiretroviral treatment to more than 100 000 patients[15]—by far the largest group in the developing world. The "Computerized System for the Control of Drug Logistics (SICLOM)"[15 24] is an internet based drug management program developed to support treatment and is considered a "key factor helping to overcome logistical challenges to delivery of antiretroviral treatment in Brazil." It connects to a central server to update its records, an approach similar to the Offline EMR in Haiti.
- The Mosoriot medical record in Kenya has been heavily used for general medical care in one hospital for more than two years and was recently extended to support HIV treatment at Moi University. It was developed using Microsoft Access; data are entered from a paper record.[14] A web based version is under development.
- The Children's Hospital in Lilongwe, Malawi, has made heavy use of a touch-screen medical record system for more than two years. Developed by Gerry Douglas, this system runs on a local network and is built using Microsoft SQL server and Visual Basic. Doctors, nurses, and other staff enter all data, including drug orders.[21] It is being extended to collect data on HIV patients.
- The Cuban health ministry has a Microsoft Access database system called SIDATRAT that registers general patient data, clinical data, opportunistic infections, staging, viral load and CD4 cell count, treatment, side effects, drug resistance, and drug adherence. It includes the more than 5000 people diagnosed with HIV in Cuba since 1986.
- A team at the US Department of Health and Human Services led by John Milberg have developed the Careware system (using Microsoft Access). It provides comprehensive tools for tracking HIV patients and their treatment. Currently used in more than 300 US health centres and hospitals, it was deployed in Uganda in October 2003. An internet accessible version is under development. Software is available free at http://hab.hrsa.gov/careware.
- FUCHIA was developed by Epicentre, the epidemiology group of Médecins Sans Frontières, to support their HIV treatment projects.[25] It supports clinical care and long term follow up of patients, including scheduling of visits, and includes data on drugs and certain investigations and generates some reports. It was developed using Microsoft Access and the Delphi programming language, and the software is available free at www.epicentre.msf.org.

Internet based medical record systems

- The PIH-EMR system was created to support the management of drug resistant tuberculosis in Peru.[16] This system was built using the Linux operating system, Apache web server, Tomcat Java Servlet engine, and Oracle database. It supports clinical care, logistics such as assessment of drug requirements, and research studies. Heavily used for more than two years, most data are entered from paper forms, with nurse entry of drug orders now implemented in some sites.

Web based collaboration and telemedicine systems (not specifically for HIV)

- The RAFT project permits remote collaboration, case discussion, and data sharing over low bandwidth networks between Geneva University Hospitals and Bamako, Mali.[26] The collaboration is being extended to other French west African countries. It is built using Linux and other open source software.
- The IPATH server allows image sharing in pathology and radiology and is being used in South Africa and the Pacific as well as Switzerland.[27] It is built with open source software and is available free at www.sourceforge.net
- Telemedmail is a secure email and web based telemedicine system under evaluation in South Africa and Peru; it was built using Java and open source software[12] and is available free at www.sourceforge.net
- Satellife are using the cell phone network in Uganda to transfer data to a central site. Local healthcare workers collect data on Palm Pilots and then connect to a local, battery powered server called a Wide Ray Jack. This server allows data to be sent to and from a central database via a cell phone modem. More information is at http://pda.healthnet.org/

Summary points

Recent studies have shown the feasibility of treating HIV/AIDS in developing countries

Lack of infrastructure, including information and communication systems, is considered a barrier to successful HIV treatment programmes

Internet based information systems offer a way to provide communication infrastructure in remote, resource-poor areas such as rural Haiti

A web based medical record system can be effectively used to track clinical outcomes, laboratory tests and drug supplies, and create reports for funding agencies

Development and evaluation of practical, low cost clinical information systems should be a priority in rolling out HIV treatment in developing countries

quickly expand HIV treatment in resource poor areas. Unfortunately projects tend to "go it alone" rather than collaborating. We are working with the WHO and the US Government Health Resources and Services Agency and others to develop common data models, components, and designs for HIV information systems. Local staff with training in information systems are also required, and we have set up a masters degree programme in medical informatics with colleagues at the University of Kwa-Zulu Natal, South Africa, and Tufts University, USA.

HIV treatment does not occur in isolation, and the infrastructure we have developed in central Haiti is augmenting the care of other acute and chronic diseases, including tuberculosis and heart disease. The similar web based tuberculosis electronic medical record in Peru provides important support for treatment, drug supply, and research with more than 2500 complete patient records entered to date.[16] We plan to make our HIV-EMR available to other organisations once it is complete, using an open source model for software distribution.[30]

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